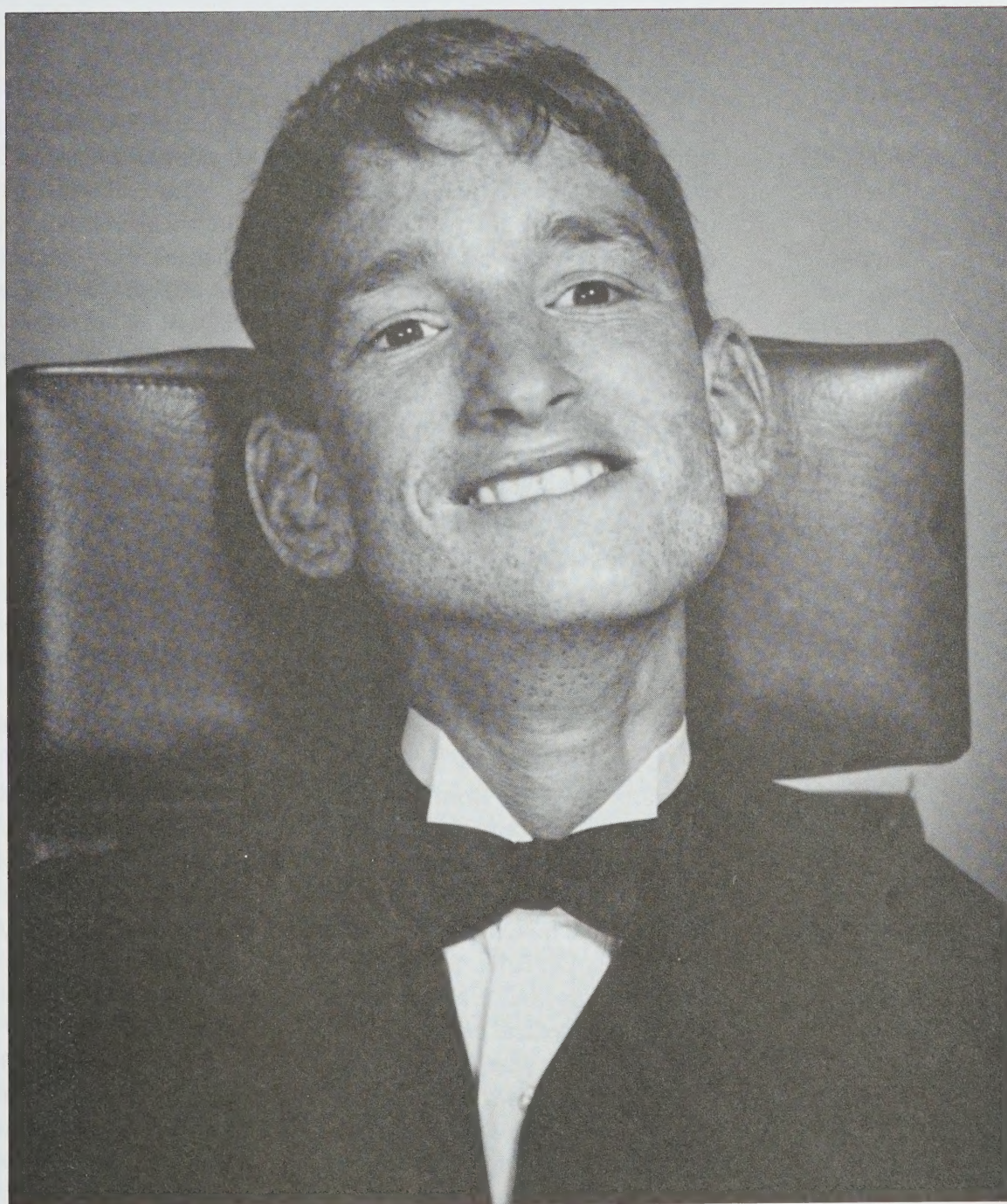


COMMUNICATING TOGETHER

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A QUARTERLY MAGAZINE ABOUT AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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SHIRLEY McNAUGHTON &
PETER LINDSAY

When our associate editors team met last March, the theme of aging was supported unanimously. The experiences of many of our friends were providing striking evidence of the differences and similarities of the aging process for those with and without major physical disabilities. Our attention was directed to life passages as well, where we saw great differences in the stages typically associated with aging. Little did we realize that those of us who knew Andrew Murphy would be forced to recognize the severe impact of aging upon this young man whom we had known since he was six years old. Andrew died on July 7, 1994 at age twenty-six. That his body would succumb to pneumonia at such a young age saddened us greatly.

If we measure Andrew's life by the same yardstick as those who are able-bodied, we would have to conclude that he moved through few of life's typical passages. We would also realize it was not for lack of trying. Andrew struggled all of his life for independence but his severe physical and speech impairments placed strong obstacles in his path. His untimely death as a young man was especially tragic as he seemed to be within grasp of achieving the independent living situation that he so desired in his life.

Fortunately we have his many articles in **Communicating Together** that chronicle, in his own words, Andrew's struggles with life's challenge. Through these articles, we can look back on the unique life passages of this remarkable young man. His determination and the

support of his family kept him forever striving forward and achieving new goals.

This issue of **Communicating Together** then is dedicated to Andrew Murphy and his family. In our feature section, we share a collection of Andrew's and his father's writings throughout the eighties, as well as some messages about Andrew, as his family and friends reflected upon his life. One of the *Wows* is an article by a young reporter who was profoundly affected by Andrew's courage and spirit even though she knew him for only a few days. Kari Harrington, a former associate editor of **Communicating Together**, also writes of Andrew's impact on her.

**Once in a while we meet someone
who stands out from the rest of
the flock; someone who flies
faster and farther and higher
than we ever thought possible,
and helps us to do the same.**

Rev. Gregory E. S. Malovetz
Pastor, St. Charles Borromeo,
Skillman, N.J.

The *Perspectives* by Dr. Brian Schwartz and Alice Born provide us with valuable information regarding the health, physical and psychosocial issues relating to physical disability and how these can impact upon aging. Dr. Brian Schwartz shares the knowledge he has gained through his medical practice in which, over the years, he has served over twenty patients with cerebral palsy as well as a number of persons with other disabilities such as paraplegia, muscular dystrophy and multiple sclerosis. He offers advice

in a sensitive and clear fashion around issues related to nutrition, mobility, communication and medical care. Alice Born describes how the effects of aging may be experienced earlier by those with severe physical disabilities and recognizes the psychological and social, as well as the physical stress that can accompany loss of independence and control. We are reminded by Dr. Schwartz of how those who are able-bodied can learn from those with disabilities, for often they have arrived at life's challenges earlier and to a more severe degree than those without disabilities.

Geb Verburg deals with aging and life transitions through examining changes in the amount of control we have. Through describing the situations of two persons with whom he has worked, Geb examines how different motivations can lead to different consequences as control is acquired or lost. He points out how the "firsts" in each child's life can come later for children with disabilities and can sometimes be missed completely with the concomitant lost opportunity for learning. In *Consuming Technology*, Robert Haaf describes the need to consider the changing communication strategies needed as individuals age and the importance of the individual assuming increasing responsibility for decision-making regarding the most appropriate method for communication in a given situation. In *SymbolTalk* there is further attention given to the growing control that AAC users should have as they approach adulthood.

When all is said and done, however, it is through observing the daily events in the lives of persons with challenges similar to those of Andrew Murphy that we come face to face with the aging process! As we who

are able-bodied consider our own lives and those of our children and grandchildren, we think of the many life passages that we all experience — walking independently, eating independently, staying at nursery school without a parent, first day of kindergarten, first “overnight” with a friend, first stay at camp for a week or a month, first date, beginning and completing high school and university, beginning a career, living away from the family home, marriage, becoming a parent, getting promotions, changing jobs, retiring, becoming a grandparent, dying in old age. We know these passages will be experienced very differently by those with severe physical impairments and their families. Many may be experienced only with great stress or may be missed altogether. The question we must ask is how those who have disabilities and those close to them can accept and value the different life patterns associated with physical limitations. The achievements will be different. But surely they require as much or more determination, self discipline, competent use of control and energy as is needed by the able-bodied person. Surely, they also deserve equal or greater recognition.

For those who are able-bodied, the community in which they live supports and celebrates their life transitions. With our strong emphasis upon integration, those with disabilities may lack a community which can share and rejoice in their particular life passages. As we considered this editorial, we could not refrain from asking ourselves what is done by schools and agencies to recognize the unique life passages of those with physical disabilities. What do we do to foster an appreciation and understanding of the differences and similarities in aging between those with and without disabilities? How spontaneously do we recognize the unique passages such as directing attendants, or pre-planning minute

details of a daily excursion or a weekend visit, or managing money and planning meals without the opportunity of handling the currency or preparing the food, or mastering the strategies required to use communication technology, or managing many pieces of complex technology, or coordinating the input of rehabilitation team members or arriving at independent decisions when family, professionals and agencies all have input and varying agendas and degrees of control? Do we recognize and applaud the strength it requires to follow a path no one else in one's social environment is taking?

And who will provide the support that is needed? As long as they are in school, most educational systems do try to provide special assistance to the developing child with profound physical disabilities. Speech pathologists, special educators, occupational therapists gather to help the child and his or her family. The support they provide is often restricted to the technical features of the child's world — communication systems, seating or adaptations to the curriculum that may be needed. They do not focus on supporting the overall psychological well-being of the children and the milestones they are trying to achieve in their unique passage into adulthood. They do not focus on preparing the environment so that it honours and celebrates the unique passages and accomplishments the child is achieving.

Nor do they necessarily adjust their normal practices to a potentially unique and possibly dramatically shortened developmental pathway. Andrew's life teaches us that the journey may indeed be very short. How should typical expectations be altered? What things must become priorities? As we failed to do in Andrew's case, we somehow must learn how to convince bureaucracies that they don't have the luxury of leisurely decision-making and deferred action.

Moreover, what do we do for the individuals themselves? How can we

prepare them and support them if they, like Andrew, do begin to experience the “signs of aging” in their twenties? We have learned from Annalu Waller and Kari Harrington (**Communicating Together**, March, 1994) that even the most successful and confident individuals with cerebral palsy can be quickly devastated by incapacitating ailments that make an unexpected appearance. Frequently, professionals lack the knowledge about how to deal with these “mysterious” conditions and our lack of knowledge compounds the whole situation.

Finally, even if a family has the good fortune to find unusually helpful professionals for their child during his or her school years, all of that support can disappear as soon as the individual leaves school. One of the parents we interviewed to gather information about their experiences with professionals (see June, 1994 issue) is representative of the many parents who are in exactly that position. At the time of the interview, her daughter had just used up her school-age credits and support was terminated. She was essentially sent home where, without the daily stimulation of school, she was rapidly losing many of the skills she had steadfastly acquired. Her parent, eager for something to provide continued stimulation for her daughter was resolutely searching for alternative programs, mostly to no avail. Another parent has responded by forming a group to build supportive housing. The former parent was considering moving to a location where there might be a program or a place for her daughter. Both were saddened and perplexed by the sudden loss of support for their daughters.

As we pay tribute to Andrew Murphy and his family we hope our readers will be motivated to consider aging as it is experienced by us all and celebrate the different pathways as well as the passages we all share.

§

Celebrating the Life of Andrew Murphy

Those who have been readers of *Communicating Together* since the eighties will remember the many articles by Andrew Murphy and his dad, Mark. In all, they wrote eighteen pieces for the Family and Community section. On July 7, 1994, Andrew Murphy died of pneumonia, at age twenty-six. We share his family's deep sense of loss.

We treasure the long association we had with Andrew and we wish to celebrate and remember his life through dedicating this issue of *Communicating Together* to his memory. In so doing, we honour and pay tribute to his mother, Francine, his father, Mark, his brothers, Mark and Jeffrey and his sister, Erin, for their caring and their understanding of Andrew's aspirations. As we reflect on Andrew's life through his writing, we urge all individuals who know the difficulties imposed on those with severe speech and physical impairments to strive for a more humane and sensitive society.



Andrew with his family:
mother, Francine, father, Mark,
brothers Patrick & Jeff and sister Erin.

Christmas, 1992

Many changes are needed before the hopes of those with severe disabilities can be fully realized. Many compromises had to be made by Andrew — many more than we would wish for a young person dreaming of his future. As we consider aging and life's passages in this issue, we are struck with the very short life Andrew had and the many transitions which he missed. His fragile physical condition was always challenging his desire for accomplishment and greater independence. Nonetheless, Andrew's keen mind and strong resolve, in partnership with his family's determination, kept him forever trying to reach his goals. Along the way, he learned a great deal and frequently shared his thoughts with us. We feel the best way to honour Andrew is to look back and share excerpts from the articles he wrote with his father, beginning in 1982 with our Inaugural Edition.

Events to Remember

Age 14: (Fall, 1982)

Introduction

Hi, my name is Andrew Murphy. I am 14 years old and have cerebral palsy. I have been using Blissymbols to talk to my family and teachers for almost eight years. I can't control my hands, so I use eye pointing to show which symbol I want to use. I like going to the theatre, the ballet and the symphony. Recently, I saw Evita.... My dad and I want to tell teachers and other people what it's like for families with children who can't speak... We want to make sure people understand the problems we have with these other ways of communicating and some of the fun things that happen when we try to use them.... (Re camp) It was fun

when I was away and we were doing something different every day, but after I got home from camp it was boring on the days we didn't do anything special. But since then, when my brothers and sister do things I can't do and I have to stay quiet and maybe watch TV for a few hours, I joke with my mother and say, "Now it's my turn to 'vege'."

Age 15: (Winter, 1983)

Anger

(Re hockey game at Maple Leaf Gardens)

I was very excited to go myself, but my parents explained to me that I couldn't go because there were too many steps and it was too difficult to get my wheelchair up there. So I got angry and started to scream. My parents wondered why I was screaming. They asked if I understood why

I couldn't go, and when I said yes, they said they felt I should understand and be quiet. But I was still angry and I still felt like screaming. Finally, my mother said it was fine and that I could scream if I wanted to; that it was natural for me to want to scream when I was angry. After twenty minutes of screaming, I felt a little better.

Age 16: (February, 1984)

Loneliness

I went to stay at the Ontario Crippled Children's Centre Hospital when my parents went away for one week. It was a very hard time for me. Because I am not able to relax in a new situation, I become very tense and I was unable to eat with all the different staff looking after me. I tried to talk to the staff, I tried to get

their attention by making noise, but it just didn't work. Because I communicate only with my eyes on my Bliss board, it takes more time for people to talk to me or listen to me. I was mad and I was lonesome, but I had visitors that cheered me up and brought me food. My teachers and friends came.

Age 16: (September, 1984) **Helping**

People who are permanently "disabled" are generally the ones being helped by others. In each of our lives, however, we all need help from someone at certain times and everyone is capable of helping another person in one way or another. Being able to help a friend gives us a nice feeling. Recently, a good friend of mine, whom I had met as a volunteer at school, had to be admitted to hospital.... When I first went to visit her I felt strange and uncomfortable with the other patients. Then I became used to them and their different ways and forgot about myself and was able to relax and make my friend happy each time I went.... My brothers and sister have a lot of friends who are often over at our house.... I wish they would take the time to learn to communicate directly so that I would be able to answer their questions and ask them questions about what they are doing. This would certainly help me enjoy my time when they are around. And, who knows? Maybe sometime in the future I would be able to help them by being able to communicate with them.

Because my aunt and uncle took the time, I was able to communicate really well with my Blissymbols and eye pointing. Not once during the week was I frustrated or unable to express my thoughts. It was a terrific experience for me. I had a wonderful time.....Now it's back to school and

another year of learning and working on the computer. I am going to spend time learning to read.

Age 17: (June, 1985) **Skiing**

Everyone else in my family skis and I have found it frustrating since I wasn't able to join them. I communicated this feeling to one of my "special friends" and much to my surprise, she arranged for me to go skiing on my birthday.... She arranged for the ski instructors to take me up and down the hill on the ski patrol toboggan. It was a terrific experience and a real thrill.

Because my aunt and uncle took the time, I was able to communicate really well with my Blissymbols and eye pointing. Not once during the week was I frustrated or unable to express my thoughts. It was a terrific experience for me.

Age 18 (March, 1986) **Moving**

Along with my family, I moved to Clearwater, Florida, during the Canadian Thanksgiving weekend. We have a very nice home, and my bedroom is on the ground floor which makes it much easier for my mother to take care of me. I like my school very much.... My teacher Carol is very kind and interested in learning how to use the computer with nonspeaking people.... I miss all my friends very much. It gets quite boring since I don't have friends to take me out on the weekends. If I get to know more people I can do more things and enjoy what Florida has to offer.

Age 18: (June, 1986) **Integration**

In the last issue, I mentioned that I was going to have an operation to eliminate my drooling. Well, I had it done over the Christmas holidays, and while I was very uncomfortable initially, the operation was a success. Now, my face is always dry, and I feel much more comfortable. You may ask what this has to do with communication. Well, a lot of communication comes from "body language" and "expression". Looking better, as I do now, encourages other people to want to interact with me.... I go out of my class for handicapped students for three periods each day...I enjoy being with the non-handicapped kids, although they are very shy and have not taken the time to learn how to communicate with me.

Age 18: (December, 1986) **Friends**

There are not many friends outside my family whom I can talk to. And after all, there are only certain things you can talk about with your family, especially your parents. In Toronto, I have a few good friends who spent lots of time talking with me. I enjoyed these long talks and miss them. My goal this year is to make new friends in Florida with whom I can communicate.

Age 19 (June, 1987) **Communication**

I just celebrated my nineteenth birthday. It was a good time to think back about how my ability to communicate has changed over the years. At the beginning, the fact that I could not speak made communicating very difficult and frustrating. It was a guessing game. People, mostly my parents, had to guess what I was

thinking, and I had to react in a positive or negative manner to let them know if they were on the right track. Thankfully, Blissymbols were discovered, and I started using them back in 1974. I hate to think what would have happened if they had not been available. My experience with Blissymbols has been very positive, and I was able to grow along with the system and develop a full range of communication abilities. This allowed me to participate in and enjoy life a lot more. Now when I look at my board, I see that there are no longer Blissymbols on it. It is completely filled with words and with the alphabet and numerals. We update the words on the board periodically, and this gives me a chance to communicate effectively with those people who take the time to interact with me.

Age 21: (March, 1989) **Independence**

In 1987 I had such a great experience canoeing in Northern Ontario with Wilderness Inquiry, I decided to go again this year....It's always a great experience for me. I liked being with different people. I find it so interesting — home is so boring. I like being in a different environment.... That first night, we slept in our tents on Sheila's lawn... Nancy, Dave and I were together in the canoe and they kept rocking it until it tipped over — it turned out to be fun. We did it three times... That night after dinner, Dave came up with the idea of giving me a drink with a squirt bottle used by cyclists — it worked! I liked it right away. . . . We had five portages in one day.... I felt very good about this trip. I thought I was becoming quite independent of my parents. I had flown to and from Minneapolis without them. I thought this was a good start in getting ready

to go away to college. Now that I'm a senior, this is very important to me. I feel more mature and I know more about life.

Age 22: (March 1990)

(written by Kari Harrington after receiving a letter from Andrew)

This year Andrew is taking three courses, Philosophy, Introduction to Art, and Computers, as well as spending two hours a day on his new communication system and extra writing classes to improve his writing skills. . . . There must be many times when Andrew feels exhausted, but in his letter he writes about how it is all worth it. He loves Edinboro University and the great people there who are so caring and he loves the freedom of being away and doing anything he wants. This balances all the responsibility he has, and makes him feel very adult and independent.

Everybody thinks about the future. We all hope and try to plan for a better life. What that means to each of us will vary. I am no different and spend a lot of time thinking about my future.

Age 24: (September, 1992) **The Future**

What does the future hold? Everybody thinks about the future. We all hope and try to plan for a better life. What that means to each of us will vary. I am no different and spend a lot of time thinking about my future. Thinking about finishing my education so I can get a job. Thinking about developing the skills so I can live on my own, with

help of course. Thinking about making new friends and staying in touch with my old friends. Thinking about seeing more of the world and how I can make it a better place.

Last year I successfully completed the fall semester at Edinboro University. On the way home for Christmas, I spent a few days in Pittsburgh Children's Hospital being tested on a new drug called baclofen to see if it would help control the tenseness and spasticity in my body. After the test, I thought it would work. We then had to decide when I would have this pump implanted in my abdomen which would administer the drug through a catheter to my spinal cord.

In January, I returned to school looking forward to the challenges of a new year. Unfortunately, my body didn't cooperate. I became tense very often and was biting my mouth so badly that the people at Edinboro were not able to take care of me. I had to return home. Since we were moving to New Jersey in April, I enrolled at St. Petersburg Junior College and took a course in creative writing which I enjoyed very much.

Since New Jersey was a lot closer to Pittsburgh than Florida, we decided to wait until we were in New Jersey to have the pump put in. On May 19th I had the operation and stayed in Pittsburgh for observation. The medication helped my arms and legs become looser. We returned home with high expectations.

Unfortunately, the catheter "kinked" and the medication stopped getting into my system. I had to go into the Robert Wood Johnson Hospital in New Jersey to have it fixed. When it started working again, my body started relaxing, however, the tenseness seemed to go into my face and I was having even more difficulty opening my mouth.

This created more tension at home as we planned for the fall. My hope was to return to Edinboro. However, since I was having difficulty we had to look for other alternatives. We found a transitional living centre that seemed as if it might be a good place to learn independent living skills.

I had also enrolled in a two-week augmentative communication course at the Temple University Summer Institute. It was great and I learned a lot about the computer. I made new friends who were dealing with their physical disabilities and still doing great things, and they had good people take care of me. I came home excited about going back to Edinboro and convinced that that was what I wanted to do. However, I still had this problem with the tenseness in my jaw and the biting.

We went to ISAAC in Philadelphia. It was great to see old friends again. It was great to listen to Mike Williams and hear what they are doing to make the world better for disabled people. It made me even more determined than ever to go back to Edinboro. But still my body would not cooperate. The tenseness in my jaw was getting worse and I was having some very bad bites. I made a decision to stop the baclofen I was receiving. While we were reducing the amount of baclofen I was receiving, I could feel the tenseness return to my arms and my legs but my jaw didn't get much better. That made me very worried about the future.

I went to see the doctor in Philadelphia to have botulism toxin injected into the muscles in my cheeks. This did relax my jaw and I was able to return to Edinboro. I was sure that was where I wanted to be, but I got pneumonia and had to return home before school even started.

What does the future hold? Where to, from here? If you have any thoughts about how I can get better control of my body, I would like very much to hear from you.

Events in Andrew's life since 1992

September 92

Andrew returned to Edinboro but did have a recurrent bout of pneumonia which necessitated his return home. He quickly recovered and immediately began taking courses at the local community college.

January 93

Back to Edinboro. Andrew was so determined to be independent — two weeks later he was back home with pneumonia.

August 93

Accepted into the Gold Crest Co-op in Toronto.

February 94:

Moved to Toronto

April 94

Operation for G.I. tube to improve his nutrition and lessen chances of aspiration pneumonia.

May 94:

Pneumonia

July 94

Pneumonia recurred.

On July 7th,

Andrew passed away.

August, 94

An Update from Andrew's Mother, Francine

While Andrew was attending Edinboro University, he was asked to be a Beta Tester for the "Liberator". He was so excited right from the beginning. His speech output improved dramatically and he was

able to communicate with everyone, even to the point of being dropped off at the "Gap" and asking the saleswoman for "Jeans please, size 26-32".

His improved communication skills also allowed him to attend a Bible Study group in Princeton and make a whole new group of friends totally on his own.

Andrew was so excited about being accepted into the Gold Crest Co-op in August, 93. He really believed and had the confidence to live on his own. He demonstrated this admirably in the preparation he gave to his interview for Gold Crest and in the capable way in which he responded as questions were asked during his initial meeting with the Gold Crest committee. Andrew wanted the independence to direct his own care, to return to the University and to complete his degree.

Unfortunately, Andrew's dream never did get realized. The Co-op at the time of his death still had not received government approval to go ahead and Andrew died from pneumonia at Participation House in Brantford four days after his parents left him there for respite care.

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We have heard about the events in Andrew's life and his thoughts about those events. We turn now to some tributes to Andrew. All of them reflect the profound effect this young man had on the lives of those around him.

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Tributes to Andrew

A Tribute from Rev. Gregory at Andrew's Funeral.

I have lived a rather fortunate life; my position as a priest and my

travels have allowed me to meet all kinds of people who do all kinds of incredible things. And in those moments, I am not only awed, but challenged and moved to ask deeper questions about my life, my journey, my flight. One of those who stood out for me is Andrew Murphy—for to meet him, to talk with him, to be with him was to recognize that you were in the presence of a man who had done incredible things—but also one who challenged and moved us to ask deeper questions about our own life, our own journey, our own flight. Andrew's journey has come to an end; too fast, too soon, with so many miles and promises yet to keep. While his sudden death saddens all of us, it is his life, his wonderful life, that stands before us as a powerful witness of the power of God at work in the world.

Andrew's Father, Mark, reflecting on Andrew's Life

"Life is difficult". This is the first sentence from a well known book entitled "The Road Less Travelled". The author tells us that only when we accept that life is difficult, can we deal with the difficulties we face in a positive manner. If we expect life to be easy, then we have great difficulty in dealing with the problems and spend a lot of time grumbling and complaining. When Andrew and I first read this sentence, he had a lot of difficulty understanding why life should be difficult. Unfortunately, no matter how much we discussed it, I was unable to explain to him in a satisfactory manner why the good Lord would want life to be difficult.

All Andrew wanted was for people to be happy in doing what they wanted to do. All Andrew wanted was to do what everyone else

was doing. Whether this was studying at Edinboro University, whether this was on a canoe trip with Wilderness Inquiry, whether this was sitting around the pool with friends and family, whether this was being together at Christmas, New Year's Eve, sitting by the river, cutting down a Christmas tree or being out with his cousins in downtown Montreal; this was when Andrew was happiest. Each of you affected his life, just as he affected each of our lives.

Thoughts About Andrew by Kari Harrington

(Kari is a former Associate Editor of *Communicating Together*)

Although I met Andrew at many different Blissymbols meetings in the early days of Blissymbolics, I never really had the opportunity to get to know him. We were often at Blue Mountain Camp at the same time, but somehow, the girls never got to know the boys that well! It wasn't until Andrew began writing the *Family and Community* column in our publication, *Communicating Together*, that I learned a little more about him.

I always read Andrew's column first because he did so many interesting things, that were fun to read.

I finally had a chance to have my first conversations with Andrew when he came to Participation House, Markham, for a short stay. He had his Liberator and I, my Epson, which worked out very well for both of us. I learned how he felt about things and I was able to tell him my point of view. I wish there had been time for us to talk more. I admired his determination and courage so much. We will all miss him, but we will remember him always.

.....

We wish Andrew had had longer to discover where his life would lead. We know he would have accomplished even more! We also know there would have been many disappointments along the road. His last few months in Toronto, hoping to live in an independent apartment, were filled with frustration for Andrew and his mother and for the other persons waiting to move into the promised apartments with attendant care. Government delays were continuously thwarting their plans. It is difficult not to notice the different positions being taken by the church and the state, during Andrew's last year.

The church has been there for Andrew and his family, to celebrate and support Andrew's living. It was there as well, to honour his life and help his family as they grieved their loss. The state, on the other hand, as represented by government policy and institutional attitudes, supported Andrew's existence but gave minimal support to the quality of his life.

The increasing measures of restraint in governmental expenditures are having a profound effect upon the lives of those with severe disabilities. We have a long way to go to ensure that, in the future, young people like Andrew will have the opportunity to participate in the life experiences their accomplishments lead them to expect and we would wish for them. Andrew's writings tell us much about the difficulties he and others with his degree of disability must face and the experiences that can bring joy and balance to their lives. He has given us the knowledge, and hopefully the will, to help others with similar challenges. We will remember!

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A Tribute To A Friend

KRISTINA ARENA

It is with great honour and yet with great sadness that I stand before you today to pay tribute to Andrew and his family.

On Thursday I lost a dear friend who was very special to me. There is so much history between Andrew, his family and myself that it is difficult to know where to begin.

Andrew and I met 14 years ago at his school. Little did I know that the relationship with Andrew, his family and myself would impact on my life so significantly.

He and I quickly became members of the Mutual Admiration Society – mutual admiration for one another in our case. I remember being attracted to Andrew's eyes which seemed to dance when you spoke with him and which followed your every move. He also had a beautiful smile that lit up a room. The special bond that developed between us remained throughout our years of friendship.

Andrew and I had many mutual interests but one of our common interests stood above the rest and this was our love for talking. And talk we did! We had many many talks over the years, and I found his curiosity about the world both endearing and a little intimidating. He had this wonderful knack for asking very direct questions which left me momentarily speechless on more than one occasion! For those of you who know me, you know that this is no small feat.

Francine would often find us with mischievous grins on our faces. She was usually curious what we had talked about to which I would laughingly reply "Oh...things". Our laughter was merely a reflection of the joy Andrew and I experienced when we spent time together. Aside from being a good communicator Andrew was a great listener. On many occasions I would talk to him about things in my

life and he would convey his attentiveness with those beautiful eyes.

In talking about Andrew, I have to talk about his family. Andrew had a very, very special family. Not only did his family provide him with the best care possible, they also provided him with so many opportunities to do things that most of us in the "able-bodied" world take for granted – swimming, canoe trips, riding on the back of his dad's bicycle, ferris wheel rides, boat rides, sleeping on the Thompson's boat, concerts, theatre, football games, baseball games and so much more.

I remember being attracted to Andrew's eyes which seemed to dance when you spoke with him and which followed your every move.

On Sunday, Francine told me that Andrew, with his great sense of adventure, had wanted to go bungee-jumping at one point! I can't even imagine myself going bungee-jumping, but then there were many areas in which Andrew was more brave than I was. He never saw himself as limited through his physical disability and I attribute his belief that he could do anything to his parents' willingness to involve him in so many activities and adventures.

I think it is significant that wherever Andrew went he forged bonds of friendship with the people around him and those who cared for him. I believe this speaks to his charm and personality. Obviously, his "dancing eyes" and quick wit had an impact on many others besides myself.

Andrew was the most courageous person I ever met! He faced so many challenges on a day to day basis that most of us will never face. Although I

knew he had moments of sadness, I was always amazed at his determination to achieve the most he could in any given situation. He seemed to have inherited this trait from his parents. I'm sure many of us here today have wondered if under similar circumstances we would have had the same inner strength that Andrew showed in dealing with his physical challenges.

He and I were both strong believers in Fate, and perhaps it was fate that Andrew was able to return to the city and people he so loved, through his mom and dad's tremendous support during this transition, in what was to become the last 5 months of his life. I'm grateful that during this time he and I were able to see more of one another, and that we were able to talk at length on many occasions.

I don't think any of us here today can even begin to imagine what these last few days have been like for Mark, Francine, Mark Patrick, Jeff and Erin, as well as for Andrew's grandparents and extended family.

I know that all of us here today share in their loss. In the days ahead, I hope that they can take some comfort in knowing that although Andrew has moved beyond us physically, his spirit lives on in all of us whose lives he touched so profoundly.

I would like to thank Francine and Mark for having given me an opportunity to be such a significant part of Andrew's life.

I will miss so many things about him. Yet, I take comfort in knowing that a place in my heart will always belong to the memories I have, of the times I spent with Andrew and his family. I trust that those memories will glow continuously like a beacon of light within me.

On behalf of us all, may Andrew rest in peace.

Yucks & Wows!

NOLA MILLIN

For this issue, we have two Yucks & Wows. The first Wow is an article by Anne Bancroft, a correspondent for the Minneapolis Star Tribune, that appeared in her July 22 Minnesota Journal column. It reflects how a relative stranger was profoundly affected by her brief contact with Andrew Murphy to whom this issue is dedicated.

Second, I am going to share a poem I wrote a few years ago that I think ties into our theme of aging perfectly. It talks about the process of a relationship. Relationships change with age as the two individuals grow and develop a trust with each other. In my mind, time only enhances the bond between you and your best friend.

Remember, dear readers, I am hoping to hear about your Yucks & Wows in time for the December issue.

Adventure – Wilds Provide a Lesson in Life:

ANNE BANCROFT

Several years ago, my life was touched in a profound way. My job was to introduce a 19-year-old man named Andrew to the wilderness, giving him the basic tools to enjoy the portages and lakes of the north. But it was Andrew who would do the teaching. For his first trip away from home, Andrew chose an adventure with a group of strangers in a program called Wilderness Inquiry. He came with a spirit of adventure — and cerebral palsy. Andrew, who expressed himself using a word board, enthusiastically navigated us through a puzzle of islands on a lake, and gently encouraged others to use his board. Unable to swat mosquitoes, dab sun block on burned ears or turn over on the ground, Andrew participated fully nonetheless — and produced an indelible memory for me.

Caged Bird

I was like a caged bird.

sheltered from the risk of being hurt,
Closed off from getting near to others,
Protected from the surroundings.

You had always been a familiar stranger.

I wasn't sure of your intent,
Frightened as you approached,
Timidly, I came nearer to the edge of my cage.

You opened the door and watched me.

No fast moves were made to startle me,
Nor did you lure with persuasions,
Instead you allowed me to venture out.

You did not grab and pull at me.

Gently speaking and assuring me,
That you would protect me,
So on your hand, I came.

You taught me how to trust.

For you wouldn't harm me,
When I share intimate thoughts.
Nor did you laugh and toss me about.

You proceeded to teach me how to be free.

I gained confidence to fly,
Knowing I could share my dreams and failures,
For you will be there when I need a refuge.

You are now my best friend.

I don't have to be held onto any more,
I am able to soar above the clouds,
To reach the height of my potentials.

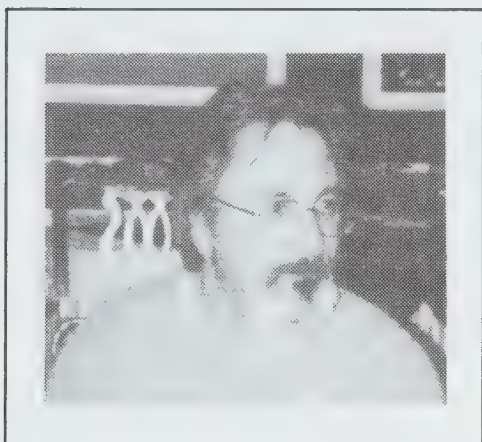
I thank you for believing in me.

For giving me courage to rid myself from my past fears,
And seeing that there can be protection with another,
Just like there was protection within my cage.

Nola Millin

Technology in Transition: Colin

ROBERT HAAF



*The theme of this issue is "transitions", and so the idea of transitions in communication technology and how we view it is the focus of this column. Jeff Higginbotham's article last issue ("What an Unlikely Couple: Minspeak and Word Prediction") was a timely one for me, as I thought about several of my clients (and Colin in particular), and also as I and a colleague were conducting a two-week Minspeak summer group just as Jeff's article came out. So, I decided to share these thoughts, in the hope that they will promote discussion among **Communicating Together** readers on a topic that I feel is crucial.*

A couple of years ago, when I first started working at Thames Valley Children's Centre (TVCC), I began working with a young man named Colin. At the time, he was using a Light Talker with Words Strategy™, which he accessed by means of his wheelchair joystick. I

soon discovered several things about Colin: (1) he was a remarkably bright individual with a good sense of his own needs in communication as well as in all other areas; (2) he had a good working knowledge of Words Strategy™ and all of the functions of his Light Talker; (3) even with these skills he rarely used his Light Talker for functional communication, at least not without considerable prompting. In fact, Colin had a two-page Blissymbol/word and spelling overlay that he could directly access and that he used quite often throughout the day, usually to spell individual words and have his partner guess. Those who know Colin can confirm that he can't exactly be described as "shy": he loves to talk with anyone at any time. In day-to-day interactions, his spelling display was often velcroed to the front of his Light Talker, covering the Words Strategy™ overlay.

The "Right" Device for Colin

It was thought by most of the professionals working with Colin (myself included) that access was the central issue in this "problem". Joystick access to the Light Talker was quite laborious. Colin often expressed his desire to directly access his voice output device in the same way that he used his light-tech display. He had tried a Touch Talker and other direct-access devices in the past, with little success.

In 1992, following a change in Colin's seating and a reported improvement in his hand function, he was once again assessed using a Touch Talker. To everyone's delight, he was able to access it much more efficiently, and after just a short time

was able to press individual keys at approximately the same rate as he was able to point to items on his light-tech display. This was a considerable gain over his rate of access using the Light Talker. It was with a great sense of satisfaction and expectation that we changed his equipment to a Touch Talker with Words Strategy™.

So what happened? It would be convenient to say that this change "opened the door" for Colin by allowing him to communicate more efficiently and with a wider range of people. As you've no doubt guessed, this is not what happened. Today, Colin does use his Touch Talker more than he did his Light Talker: to talk with strangers in the hallway, to give speeches, and in some other situations. However, these situations occur only occasionally and are not integral parts of his day. Colin uses his Touch Talker most often as an interface to the computer for writing, although he continues to express his desire to type on a standard keyboard and to use a trackball. Most of the time when I see Colin, his spelling overlay is velcroed in the same spot it always was, and his primary modes of communication have not changed substantially.

I used to (good-naturedly) annoy Colin about doing this, until he would reluctantly remove the display and use the Touch Talker (always efficiently and appropriately). I stopped doing this once I faced a simple fact: Colin was making a reasonable choice about what mode of communication (spelling) was viable for him in this situation, and I had no business trying to convince

him otherwise. In fact, when I stepped back and viewed Colin's interactions more objectively, this mode was more efficient for one-on-one conversation because his partner would co-construct the message by guessing letters and words, which speeded the process enormously. Rate of access was very similar, but rate of communication differed significantly between these methods.

What does all of this mean? Does it show that Colin's voice output device is inappropriate for his needs? Probably not. To the extent that he needs to use voice output, the Touch Talker is the best choice of the systems currently available. Does it mean that Colin's care providers should have been more "diligent" in ensuring he use the Touch Talker? Maybe. However, I think that this situation represents a much more important point. It reflects a user making his own decisions about the relative merit of each of his modes of communication. Personally, I think we started being better clinicians and facilitators once we stopped trying to impose our views on Colin and realized that our role was actually to provide him with viable options for communication, to let him make his own decisions and then respect those decisions. Because Colin now has a range of communication options available to him, because he has the knowledge and understanding about how they work, and because I'm confident that he can decide where they are useful, I see Colin as a communication "success" in every way.

Back to Minspeak and Word Prediction

So how does this relate to last issue's discussion of Minspeak and word prediction? I feel that the

development of communication technology such as that described by Jeff Higginbotham helps to address the basic clinical issue I'm attempting to discuss. As a clinician, I work with many clients using Minspeak systems and word prediction programs (though seldom in conjunction), and I can attest that it's not just people like Colin who prefer modes of communication that seem on the surface to be slower or less "functional". Even individuals with decidedly "inefficient" access modes (such as scanning) quite often opt for spelling as a preferred conversational mode.

Most of the time when I see Colin, his spelling overlay is "velcroed" in the same spot it always was, and his primary modes of communication have not changed substantially.

I heartily agree with Jeff about the need to consider apparently disparate modes in conjunction, and preferably within the same device, since in my experience one encoding method is seldom sufficient for an individual throughout his or her lifetime, or for all situations at any given time. I am beginning to believe that once AAC users learn to spell functionally, they will spell, perhaps not to the exclusion of other encoding strategies but certainly as a preferred strategy. When we get bogged down in discussing encoding strategies in terms of keystroke savings, long-term memory for icon sequences, etc., we begin to ignore the functional aspects of the communication process, and the fact that

there may be many reasons an individual chooses to use a particular communication mode even if we think there is a better one available.

In the real world of the classroom and the shopping mall, many motivations take precedence over speed and keystroke efficiency. I've heard individuals say that they feel isolated when they are using a communication mode no one else in their environment uses, that support in the home and school environment is towards developing traditional orthography over the use of icon-based systems (which take a considerable amount of time and motivation from care providers as well as users). Colin once told me that whenever he uses his Touch Talker in the classroom, everyone looks up. He feels, reasonably or not, that at such times he disrupts the class more than a speaking person. And why should Colin choose to use voice output in such a situation to communicate with his aide sitting next to him?

As Jeff also points out, the technology currently available does not provide a functional alternative to those individuals, like Colin, whose vocabulary requirements far exceed the current capabilities of voice output devices. So they begin to spell, if they can; what choice do they have? Besides, everyone else around them spells and reads, or is starting to. Clinicians, caregivers, everyone has to begin to consistently respect these motivations. We need to continue to consider how we can successfully move individuals through such changes in their communication systems with a minimum of effort and frustration.

Having said this, I don't want to be perceived as "anti-Minspeak" — or (gasp!) anti-technology; some of my best friends use it! I currently

have a number of clients who are working with voice output with Minspeak Application Programs, and in almost every case I feel that this is appropriate for them at this point in time. I simply have begun to believe that encoding with icons is most often a transitional communication solution, particularly for those individuals who develop literacy skills. One aspect of this argument

In the real world of the classroom and the shopping mall, many motivations take precedence over speed and key-stroke efficiency.

that still needs to be considered is developmental: Iconic encoding strategies such as Minspeak can offer the preliterate AAC user access to a level of both speech and written output that is more in line with their language abilities, when for whatever reason orthographic skills are delayed. This is, of course, an idea that has been proposed for some time, within these pages and elsewhere.

Transitional Strategies

I truly feel that we need to begin to look at Minspeak and other encoding strategies not as static, life-long "solutions" to an individual's communication difficulties, but as (possibly) transitional strategies that are useful in certain contexts. If this is true to any degree, then the concept of providing a specific communication aid or "solution" in the form of encoding cannot be clinically supported. It is perhaps a step towards clarifying the perceptions of many working in AAC about why so many communication devices "fail". Perhaps they don't fail for the user. Perhaps they only "fail" for the

clinicians who have global expectations about how and when such devices can reasonably be used.

Changes for the Future

In considering the future development of communication devices, one issue of Jeff's discussion last issue that was particularly exciting was about proposed changes to communication devices to allow them to incorporate the kinds of changes discussed above. The "ideal" future communication device will have to incorporate all of the following:

Expansion. The 'ideal' communication aid will allow transitions between encoding strategies, methods of vocabulary storage, etc., within the same device, so that as an individual develops new skills the hardware (and preferably the access method(s)) can remain in place as long as necessary. This has obvious implications for replacement costs, training time and effort, and the amount of time needed to again use the device functionally. Thus, if Colin or any other individual wants to move from Minspeak to word prediction (or perhaps a combination), such a transition could be effected with minimal disruption of the client's communication and life.

Integration. The ideal device will also integrate face-to-face and written output modes with whatever input modes (access modes and encoding systems) are used by the client at any given time. Obviously this is being done more and more often as communication software is developed for laptop computer systems (Words + products and HandiWare spring immediately to mind).

Modularity. Based on the first two points, future communication devices should ideally employ a common hardware base, with modular software components that can be

changed easily to accommodate changing needs in access, vocabulary, encoding, etc.

... why so many communication devices "fail". Perhaps they don't fail for the user. Perhaps they only "fail" for the clinicians who have global expectations about how and when such devices can reasonably be used.

The mention of "cost" above leads me to my final point. When I have previously made comments to others about the use of technology only in specific circumstances, it has frequently led to comments about cost effectiveness: These devices cost thousands of dollars! Is it clinically responsible or worthwhile to the taxpayer, family, etc., to provide such a device for such limited usage? I have three responses to this. First, is it more cost-conscious for clinicians to provide technology bundled with a set of possibly unrealistic and punishing expectations as to its use, and therefore help to ensure that it's never used at all? Second, if a device can provide an individual with even one or two specific communication abilities that they otherwise would not have, are we prepared to make the decision as to the "value" of this based purely on cost? When we are, I will no longer be able to be a clinician. And third, if you are a clinician, developer, researcher, or administrator reading this, the question of "worth" being considered is not yours to make; we are obligated to present the realities of the costs and benefits of technology in an honest way to clients and families. The decision is theirs. Nothing could be more responsible.

AGING FOR PERSONS WITH CEREBRAL PALSY

BRIAN SCHWARTZ, M.D.



Brian Schwartz with Susan Odell, a patient of many years.

We wish there were more Dr. Schwartzs within the medical profession. We need more such sensitive and knowledgeable individuals! Dr. Schwartz has been treating persons with disabilities for over thirteen years. He has been on the Board of Directors of Participation Apartments, Metro Toronto since 1982 and is currently its president.

With many of the "baby boomer" generation reaching their mid to late forties, issues of aging have reached great importance in our culture. Since I and many of my patients are reaching that stage, these issues are very pertinent. Just as in all areas of health, there are facets common to persons with and without cerebral palsy, as well as some unique aspects to each.

In this article I will try to cover those issues which are particularly topical for individuals with cerebral palsy, especially those who lack the ability to speak to families, friends and professionals, and others who sometimes don't know what questions to ask or issues to address.

I should stress that the information I am sharing is not in any textbook or magazine but is simply my impression of aging and its challenges in my patients; that is, what I have learned from my own patients with cerebral palsy as individuals and in the community.

Before beginning, I would like to point out that many of the solutions to the problems discussed below have not been developed, either within the disabled or the non-disabled community. Perhaps a follow-up article in a few years might provide the answers to some of the questions we raise!

The ability that non-speaking individuals have developed to deal with these challenges all their lives gives them a head start on the rest of us in the communication area.

Speed of Aging

The speed of aging in people with cerebral palsy can be related to inactivity and spasticity and sometimes to the number of times an individual suffers from pneumonia that can be caused from aspiration of food due to poor swallowing. The bones become thin (osteoporosis) from the lack of activity and the body curls up and muscles atrophy due to the constant pressure of the spastic muscles.

We need to impress upon younger individuals with cerebral palsy the need to keep active, stretch, and eat properly as specific preventive measures. We must also be realistic about our expectations as we see the aging process taking place with older persons with cerebral palsy.

Nutrition

Individuals with cerebral palsy often have trouble chewing and

swallowing food. These problems may be compounded by new ones in later years, such as dental problems, worsening of spasticity, effects of muscle relaxant drugs on the swallowing mechanism and poor dietary habits based on preferences or finances.

Obesity may be a problem due to lack of regular physical activity. There are a number of things a person can do, therefore, to minimize the aging effects:

- 1) Keep good dental hygiene. This is often a low priority. Make it a high one. Visit the dentist regularly. Make sure your teeth are brushed and cleaned and get help if possible with techniques to remove bits of food from between your teeth, because this can lead to gum disease and tooth loss.
- 2) Eat properly. Choose a diet (soft or hard) based on your ability to chew and swallow. Avoid "junk" foods or at least save them for a special treat once a week! Protein supplements are available at drug stores but can be expensive. Sometimes if poor swallowing leads to serious medical problems, special feeding tubes can be used to ensure proper nutrition, but this is a last resort. Use alcohol and caffeine in moderation if at all.
- 3) Occasionally vitamins, iron and calcium supplements may be necessary depending on a person's medical status. Check with your doctor.

Mobility

This of course is a major issue the entire life of a person with cerebral palsy. Whether you need an assistive device or not, this issue will become more and more important with age.

Increasing muscle stiffness, weakness of muscles, arthritis medications and diseases such as stroke can decrease mobility and put one at risk for injury from falls or accidents.

Looking at the problems, things you can do are:

- 1) Keep active. Move your joints, even in your chair and bed. Have friends and relatives move your joints passively to minimize further stiffness and spasticity. If you have access to a pool or gym, use the facilities if this is okay with your doctor. Get out and about!
- 2) Review your medications regularly (at least twice a year) with your doctor. Muscle relaxants can cause sedation and depression, minimizing potential for activity. Pain medication can be hard on the stomach, leading to medical problems and further weakness. Proper nutrition is important and calcium supplementation may be necessary to help prevent osteoporosis which will be explained below.
- 3) Review your mobility assistive devices. With a changing body, these may not fit properly, which could lead to pressure problems, wear and tear of certain joints and accidental falls. If you have any unusual joint pain or swelling, have it assessed by your doctor or therapist.

Communication

In my experience the ability to communicate gets better with age! As many people with cerebral palsy become more independent and better educated their ability to be "word efficient" in speaking or communicating in other ways becomes more effective. I am always impressed with the ability of my non-speaking patients and friends to get their point across using as few words as possible. This can be a lesson to many of our non-challenged population!

However muscle weakness, sedation due to alcohol or medication, and medical problems such as stroke can further impair communication. Some of these issues are discussed above and below. I feel that the ability that non-speaking individuals have developed to deal with these challenges all their lives gives them a head start on the rest of us in the communication area and that the expertise they have developed in communicating can be taught to others in the general population when their disabilities set in. Come to think of it, this applies to mobility as well. Many of the issues that are new to aging non-disabled individuals in mobility and communication have been dealt with by people with cerebral palsy all their lives. We can all learn from each other on this.

In my experience the ability to communicate gets better with age!

Medical Issues

The risk of many medical problems increases with age. Regular checkups are important and should include blood pressure, assessment of weight and function of body systems, blood sugar and lipids such as cholesterol; as well as prostate examination in men and breast examination and pap smears in women. Lifestyle issues such as smoking and diet should also be discussed. Smoking is the one area that contributes the most to disease, including cancer, emphysema, strokes and heart attacks. Alcohol and drug use should be dealt with as the effects on vital organs are cumulative with time and the risk of accidents while intoxicated are increased due to some of the mobility issues discussed earlier.

Osteoporosis is a problem in non-mobile individuals. Females after menopause and persons who are wheelchair confined are at higher risk.

Regular activity is essential in preventing stiffness as described but also to prevent thinning of the bones. Dietary calcium found in dairy products (milk, cheese, ice cream) is helpful and calcium supplementation, vitamins, and possibly hormone replacement in some women may be appropriate. Discuss this with your doctor.

Some bodily functions may slow down with aging. Constipation may be a problem and increasing the amount of fibre (in bran cereal, some vegetables and fruits) in your diet is helpful. If there are any urinary difficulties or other problems with the bowels, see your doctor.

Sexual activity may sometimes change with age, but need not disappear. Increasing time to orgasm in males and less lubrication in females is normal. Because of mobility and communication issues, these changes may be difficult to surmount, but all individuals have some trouble handling them to some extent! Communicate with your partner, ask specific questions of your doctor, and remember that many body functions as described (mobility, bowels, sex) may change in quantity but not quality.

In conclusion I hope I have not painted a gloomy picture, because aging can be a very positive growth process. As we grow older, we can draw on a wealth of experience and maturity. We know ourselves and others better and can communicate more effectively. Our fuses may not be as short, and we can provide counsel to others. If we look after our physical selves, our mental, emotional and spiritual areas can take us into new challenges. In the area of cerebral palsy and other physically disabling conditions, there is room for innovation and ideas in coping with the aging process. We are on the leading edge and have the opportunity to help in developing assistive devices (both in mobility and communication), and creative ways of self-determination for physically challenged persons.

Perspective on Aging and Cerebral Palsy

ALICE M. BORN

Alice Born is a consultant in aging and cerebral palsy at the Ontario Federation for Cerebral Palsy. We are pleased that Alice agreed to share the knowledge she has gained from conducting a study on aging in 1988 followed by a workshop in 1992 for persons living with a life-long disability, their care givers and professionals. Of the references she has provided at the end of her article, we would particularly recommend "Aging with a Lifelong Physical Disability: A Self-Help Guide" edited by Alice herself.

Cerebral palsy is a disorder of movement and posture appearing at birth or in the early years of life. It is due to damage or failure to develop normally in the part of the brain controlling movement. While some people with cerebral palsy have a life span comparable to the average person, for others the disability appears to exaggerate some of the overall effects of aging that everyone encounters sooner or later. The effects of aging may be experienced at an earlier age than with the general population - sometimes as early as the late 30's or early 40's.

A Positive Attitude Helps

A positive attitude helps maintain a healthy lifestyle. Good nutrition, exercise and good friends go a long way to maintaining overall physical and mental health. Knowing that changes are going to take place as we get older and our attitude towards these changes can be our greatest asset in making the transition to the next stage in life.

Losing one's functional abilities can cause physical as well as psychological stress. Physical changes that may happen are:

- increased joint and muscle pain
- declining mobility due to bone and muscle mass losses
- abnormal stress on bones and muscles
- wear and tear on joints
- changes in gait and shift in weight bearing
- arthritic changes
- osteoporosis
- decreased endurance
- increased fatigue
- spine and joint changes affecting posture and weight bearing
- increased respiratory problems that may result in heart and lung complications
- pressure sores and skin breakdown
- reduced physical functioning and poor nutrition affecting the function of the cardiovascular system
- poor dental care in early years; poorly fitting dentures later in life affecting the function of the gastrointestinal system
- side effects from long term use of medications resulting in physical problems.

While the list of possible changes may seem daunting, it would be unusual for any one person to experience *all* the problems noted above!

Psycho-social Changes

Losing functional abilities can cause psychological, social, as well as physical stress and can be troublesome for those aging with cerebral palsy. For example, someone who has worked to overcome attitudinal and physical barriers at a younger age, may find that as they age new barriers appear.

Someone who has been employed may have a need to reduce working hours or give up employment altogether because the work or the hours may become too demanding. This loss of independence can result in feelings of frustration, depression and anxiety.

These losses — of control and independence, functional changes as well as changes in lifestyle — all contribute to feelings of anxiety and fear, especially if help in resolving the negative feelings appears to be unavailable.

Where is help available?

Family physicians who have developed a good understanding of their patient with cerebral palsy can be a valuable support to that patient as well as to family members and to caregivers. Assessments by a rehabilitation specialist and an occupational therapist can be useful tools in identifying adaptations that may improve physical functioning for those whose needs are changing as they age.

Another way a family physician can be of assistance, is ensuring that the patient is referred to a competent mental health specialist when this need has been identified. Regular review of medications is another important health consideration, as side effects from overlong use of medications can adversely affect functioning abilities of individuals aging with cerebral palsy.

The Role of the Caregiver

Caregivers, where they are an integral part of the life of those aging with cerebral palsy, may at times find themselves meeting the social, psychological as well as the physical needs of the consumer or consumers for whom they provide care. The caregiver may also be the primary

liaison with social agencies providing other professional services. The caregivers may assist in setting up appointments and in arranging transportation to and from these appointments.

When a crisis arises, the caregiver is often the person most readily available to provide emotional support. Whether the caregiver is a family member or from a community agency, they also experience anxiety, guilt, fatigue, physical illness, anger, frustration, and depression as they assist in ensuring that services are provided as needed.

Caregivers need support of others in similar circumstances, of agencies providing professional services and of the community in which they live and work.

It is important that the consumer who is getting older, and their

families or significant others be aware of what and where assistance is available and who is able to provide it.

In summary, consumers with cerebral palsy, like the general population, begin to experience unexpected changes as they begin to age. When these changes affect physical and mental health as well as lifestyle, consumers require information and assistance to enable them to understand how the changes may affect their future and to enable them to maintain control of their lifestyle. They and their caregivers need to know what help is available in the community and how best to access it. They need the support and assistance of family physicians and other community professionals to ensure that they have the opportunity to maintain their overall health as they age.

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CONTEXTS

TRANSITIONS AND CONTROL

GEB VERBURG

This article is a collection of comments about control, changes in control, and changes in people's lives as a consequence of changes in the degree of control they have. I will toss in some general musings about changes in control models in society, as I see them, of course.

Many of life's transitions have to do with a change in the amount of or method of control over our life and our roles. When we change schools, change physician or dentist, move out of the parental home into an independent living environment, or when we get married or divorced, all these changes shift the balance of power in our lives and the amount of control that we take or shun in these changing circumstances and from these transitions onwards. Other, more emotional transitions like the loss of a parent, spouse, child, sibling, or friend also have implications for our life, our roles in life, the integrity of our being and the control we feel we have or lack.

The stories and observations that follow are connected by the tenuous link of having to do with change and control or changes in control. They tie in to the context of transitions and the amount of control that people have, are given, take, or require.

Two Instances of Taking Control

About two years ago we started a project in which a number of people with disabilities worked together

with researchers to organize focus groups and review commercially available products. The project was initially coordinated by researchers but its goal was to transfer control of the project to one or a small group of persons with disabilities. After about one year's operation, a request for volunteers to take a leadership role met with limited success. One person volunteered and was successful in obtaining a grant to carry out an independent research project relating to education. At this point in time no person volunteered for the overall project leadership.

The person who took on the educational component did so with the intent of teaching society that persons with a disability can "pull their own weight", can contribute, and that education will change employer's minds into hiring more employees with disabilities. When the latter part of this perspective was not fully supported in the research and development project, a decided swing towards a more revolutionary position ensued. Just as in Michael Oliver's philosophy, society was blamed for its disabling effects or disabling conditions and an underlying anger and frustration came to the surface. The moral that I drew out of this experience is that if your goals are too high or too ambitious, you risk not only a failure to reach or accomplish the stated goals but you also run the risk of being pushed into an adversarial position that may diminish your chances of future success.

It was not until another year later that one of the initial participants, who had gradually assumed the role of focus group convener, decided that he was ready to attempt to take

on the project and develop it into a business. This participant has a high-level spinal cord injury and uses a sip and puff system to control his wheelchair, computer, and home control system.

His transition from a member of a team to a leader of a team took time, a business opportunity in the form of an invitation from a national association of Canadian businesses, and support from a family member. I do not think that these supporting factors tell the whole story. In both cases the persons who took the risk of assuming these leadership positions had no previous experience of a full-time job. Both are obviously competent persons, yet the leap into taking control was made from, in my opinion, very different perspectives.

The person taking on the overall leadership proceeded as follows. His first request was for all relevant information so that he could learn more about the evaluation process and methods. He then proceeded to draft a business plan, pursued the incorporation and legal search of the name of the project group, and in the meantime continued to convene and moderate the focus groups. His perspective or perhaps I should call it his approach is one of gradually building a basis of expertise and bolstering this with a plan and traditional business approach to running an operation. I believe that he has decided to try to make this consumer-based evaluation and consultation activity a business that can earn him a living in the near future. If he succeeds it will be his business, his success, his company, he will be in control. If he fails? I hope he won't of course. It will be a blow to his self esteem. But it will not be the end of the world because

he will have formed new connections, new relations; he will be able to benefit from what he has learned.

Control Given and Control Taken Away

For as long as I have written this column I have harangued all professionals to give as much control as possible to children who have disabilities. I do not limit this advice to disabled children. It applies equally to all. It is always difficult to decide where or when one has reached the reasonable limits of this "as much as possible". I'm afraid I cannot be extremely explicit in prescribing these boundaries. Personally I try to lead by example. I dread the thought of prohibiting my son or daughter an action which I find dangerous to them, only to learn later that they went ahead and did it as soon as I had left. I would much rather be there so I could save them, if necessary. Instead I point out the dangers to which they expose themselves and count on their rationality, timidity, or both.

For people with disabilities there are not necessarily fewer dangers in the world, but I think they are very different. Very few children in powered wheelchairs need to be warned against shooting a dangerous rapid or swimming too close to a rapid's undertow. On the other hand very few able bodied persons even know about red spots or other warnings of skin break-down that are the bane of many wheelchair riders. The number of medical conditions with dangerous sequelae increases with the increase in severity of the disabling condition. There is very little excitement in taking risks in areas of medical fragility, it is too much like playing with death.

One of the immediate consequences of medical fragility is the loss of control which occurs due to the medicalization of one's life. But even without this infringement,

persons with disabilities have fewer options, fewer opportunities to take control of their lives as readily or as early as children/persons without disabilities.

If we were to study the firsts (e.g. first step, first stair climb, first word, first smile, first trip to mall, first date, first apartment, etc.) in the lives of two groups of children, one group of disabled children and one able-bodied, there is no doubt about who would hit most firsts first. Such a list of "First ...'s" would have an alarming number of blanks for persons with disabilities. Each of these blanks is a missed transition, a missed step in the evolution of the person. These missed steps need not be disastrous but we need to realize that a person grows by conquering these firsts. Without them he or she not only misses a life- activity but she/he also misses an opportunity to learn. We should be aware of that and try to fill in these missed firsts, wherever and whenever possible.

One last example of control being taken away, is the perennial problem of assisting. I have probably sinned more than most. I am an action person. It is easier for me to do things than to talk about them (the Mars and Venus thing). So, when I am allowed to help a person in a chair or with any other device, they tend to get more than they bargained for. Always out of the goodness of my heart and so on but annoying nevertheless. I keep hoping that someone will tell me "Thank you very much but that's enough." You can you know, we'll be back for more. The best assistants are those who stand and wait to be told or shown what to do, or at least check frequently with the person whom they assist.

Control Given

To conclude I want to share two things that hold out some interesting

hope in this power struggle called living. The first is that there exists a possibility that the traditional barriers thrown up between the "ignorant masses" and the "expert few", i.e. the degree, diplomas, certifications, qualifications, associations, etc. are beginning to be eroded or even disappear as a consequence of the easy access to information in this telecommunication and information age. The old adage of "knowledge is power" may still be true but its complexion changes when everyone with a modem can get "equal" access to that knowledge. That will be such an exciting development and I will certainly write about that in one of the future issues.

The second hope, as yet more wishful than factual, exists in a change that I have observed from a very "anal retentive and domineering version" of control which is widely practiced in North America to a version of control that is more akin to "shared responsibility or coordination". This change is connected with GenX, these hopelessly brave young folks who are inheriting one of the toughest worlds possible.

In the old style of control, there was a hierarchy and the person at the top knew what was going on and was held responsible for failures anywhere in the tree. As a consequence the authority was a top-down one with compulsive reporting and punitive rather than creative solutions to problems. My observations of and (limited) relations with some of the more successful business leaders of today lead me to speculate that a new control structure is emerging. I do not know whether it is due to the reduction in middle managers or whether it reflects a belief that people lower down in the organization are capable of performing their jobs and can be held responsible for what they do or fail to do. I hope it is the latter because that would mean a re-valuation of people who had long

been devalued in the top-down control systems where their performance was often so tightly controlled that they had little or no responsibility.

It also means that people with disabilities may be able to enter a workplace where they will be held responsible for their performance and promoted for their abilities and not just hired to fill the quota of the local Employment Equity Laws. The new distributed control model is scary because as a "boss" you must learn to depend on other people rather than be in total control of the

entire process, and as an employee the entire process (or project or product) is dependent on you and every other participant to pull your and their weight.

Both the telecommunications and information revolution and (if it exists) change towards the distribution of control are movements that could be interpreted as true emergent versions of direct democracy. Telecommunication technology gives everyone (in principle at least) access to massive amounts of information. The same technology allows for people to punch in their

votes or opinions for any local, municipal, provincial, federal or global issue or question. That is, the concept (and practice) of distributed control allows people to share in the decision making. People using AAC devices may have a bit of an advantage here, with an above average computer literacy rate and potential access to e-mail or other telecommunication networks and tele-commuting opportunities.

§

PAUL'S PLACE

The Benefit and Disempowerment of Being Integrated

PAUL MARSHALL



Welcome back to Paul's Place. In June, I had a discussion regarding the professional/consumer relationship with Suzanne Clancy, a professor at Mohawk College, Hamilton, Ontario. For this issue we both want to continue our conversation.

Integration: Benefit and Disempowerment

Paul: I believe if we first start by defining the words benefit and disempowerment, then we will have something to base

our discussion on. So let's go to Suzanne and see how she would define these two words.

Suzanne: As for myself, something is of benefit if it enhances the quality of my personal and professional life, helping me be a better family member, citizen and teacher. I also feel that something beneficial should not necessarily be limited in time or concept, but can be ongoing and developmental.

If we want to be of benefit to others, we need to be ready and willing to make changes.

For myself, disempowerment is something that I don't have control over. It occurs when I don't have the input to alter the events that affect my state of being. Disempowerment is having others make even the most basic of choices and decisions about how we will live, where we will live, who we can associate with, what we will learn, and how, and the value of

our output (work). Disempowerment is the inability to make informed decisions either because of the lack of access to learning the skill or opportunity to use it.

Paul: You make some very good points. I agree with you totally. Anything that alters one's life in a negative way, we see this as disempowering upon the life-style that one chooses. Most of us would protest loudly if some of our choices were taken away. We would fight to get back some control in our own hands. If we want to be of benefit to others, we need to be ready and willing to make changes. Sometimes, this comes from strong voices for change to improved quality of life. When we are talking about the ongoing process of maintaining any relationship, whether it be professional or personal, it is important that we keep in mind the whole is greater than the parts. By this, I mean it is vital that we go the extra mile or miles to build healthy professional/consumer working relationships. The relationships that we develop today

are tomorrow's foundation of a better quality of life for many.

Suzanne: When we are talking about the benefits of being integrated, it is important that we realize that there needs to be accountability on the part of both the professional and consumer to provide positive growth. This is a win-win situation where both parties end up gaining from each other. We need to ask ourselves: If I am integrated into any number of our social programs, what do I have to offer, instead of what can integration offer me? The disempowerment of integration is when an individual or the system withholds the access to learning or limits the opportunity for personal growth. When there are limitations or barriers to development, no one wins, and both lose. Growth can't be generated to make informed decisions because of lack of knowledge.

When there are limitations or barriers to development, no one wins, and both lose.

Professional-Consumer Relationships

Paul: Consumer input to professional fields is a fairly new event. It is only in the past few years we are seeing individuals like myself being given the training and opportunity to develop the skills and make a

contribution to the field of AAC and/or in society. The question is how can these two groups work together. We know most of us have common goals. The issue that concerns many consumers is quality of their involvement when the consumer is viewed as an important part of the solution. With this comes the question whether the consumer should be paid for being involved.

What do you think Suzanne?

Suzanne: This is a difficult question for me to answer inasmuch as I get paid for what I do. However, I certainly think some form of compensation is reasonable if an individual is part of the solution. What form it should take is the dilemma. There are those who feel that the quality of the input is in direct proportion to the money received, while others feel that just making a contribution is reward enough.

I realize this does not fully address your question. Perhaps it is one that is better asked of the consumer. While I support compensating people for what they do, I hope we still have room for "free advice". Sometimes the support we need and receive is invaluable.

Paul: What I am going to say may put a rope around my neck, but I feel it needs to be said once and for all from a personal standpoint. I deeply feel, and I have taken this view as my creed, payment for what I do is not important. As long as I can have

enough to live on that is all that matters. I said before the whole is greater than the parts. Sometimes we need to realize that our lives are a fine line and "free advice" might be more important than payment by money.

I am convinced that any byproduct that will come out of any professional/consumer working relationship will be because we put great value on human dignity.

Another issue is to have equal input with the professional. I deeply believe that if any professional/consumer relationship is going to work, we must see that the input from each side is valued and needs to be taken fully into account. We must function as "one body" which has many vital ideas and comments to offer to add to the relationship.

Last but more meaningful is human dignity. I am convinced that any byproduct that will come out of any professional/consumer working relationship will be because we put great value on human dignity. You could give me a nice salary, or you could value me as a person and I would take being valued. There is no price for dignity.

I would really welcome any of your ideas or comments here at Paul's Place. This column is yours too, so write and let's talk. Write me in care of Communicating Together.

See you in December,

Paul

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Strategy Diversity

SHIRLEY McNAUGHTON

In the last issue of **Communicating Together**, Jeff Higginbotham discussed “The Marriage of Semantic Compaction and Word Prediction” and described them as an “unlikely couple”! I was very glad to see Jeff viewing these approaches as complementary rather than as competing, for it moved us closer to the day when we would recognize *all* the various strategies by which AAC users could retrieve information as compatible, so long as the individual finds them helpful. In fact, I have often expressed my hope of seeing courses developed *by* and *for* AAC users in which the many ways of storing and retrieving information could be explored. Given the opportunity to learn about alternatives, I would expect to see AAC users expanding their range of strategies — selecting those that work for them. I propose we let the two approaches of semantic compaction and word prediction serve as the starting point for considering the many cognitive strategies that could be used *purposefully* by an individual.

Before doing this, I would like to introduce an idea from a book I am enjoying very much — thanks to a suggestion by Walt Woltoz, of Words+. The book is entitled *Bright Air, Brilliant Fire: On the Matter of the Mind* (1992). It was written by neuroscientist and Nobel Laureate (1972), Gerald Edelman. There are many exciting and thought-provoking ideas in Edelman’s book, but the analogy that I wish to share in this article is his reference to the activity

of the mind (i.e. the signalling of the circuits of the brain) as resembling “the vast aggregate of interactive events in a jungle” (p. 69). Now how does Edelman’s comparison of cognition with the events of the jungle relate to Jeff Higginbotham’s partnership of semantic compaction and word prediction and my interest in a set of cognitive strategies being used to retrieve information?

The Structure of the Jungle

The *jungle* analogy serves to remind us of the complexity of the brain, hopefully not to intimidate us, but to give us a healthy respect for its interconnected and interactive structure. And going one step further for those of us who are involved in teaching, we can recognize that we will never fully understand the extensive networks within “the jungle” and that there are many relationships that will remain unknown to us. We can then proceed with as much knowledge as we can attain, with a willingness to explore and with respect for the power of our students’ minds.

Many Cognitive Strategies

Getting back to cognitive strategies for representing, storing and retrieving information: We can expect individuals to use a vast number of ways to organize and access the information that they will be communicating. The two that Jeff Higginbotham described are readily available in voice output devices and software programs. There are many others that we can consider when constructing communication boards. The preferences and abilities of the individual are the only limiting factors!

Ways of Organizing and Retrieving Symbols

First to be considered as symbols are organized on a communication board are the number, location and grouping of the symbols. These are determined in part by the physical and sensory capabilities of the individual — range of movement, ability to turn pages, targeting size, vision factors such as size, figure/ground relationships, distance, etc. Of particular interest in *SymbolTalk* are the cognitive considerations that will affect retrieval. The symbol location can be remembered by membership within a class, colour or number code, position relative to other symbols on the board, grammatical category, initial letter of referent, assigned association, etc. And then there are the more subtle strategies for retrieval — personal and experiential associations, symbol component relationships, idiosyncratic cues.

Jeff Higginbotham’s article reinforced that an individual does not have to decide on just one strategy. He discussed two approaches that can be used for word production. As we consider symbol selection, many techniques can be added through the years, depending on the developmental path of the individual.

The Child

As I consider these things, I am immediately reminded of the differences between adults and children. Although we can enjoy the “jungle” retrieval system of an adult, which has been created out of experiences that work for that individual, we would be foolish to applaud a child’s communication board that has no

planned structure. We do the young child no service by providing him or her with an "anarchy board"! So what is the difference? Why acceptance of a jungle analogy working for the adult, but not for the child?

Here, the thinking of the Russian psychologist, Vygotsky (1896 - 1934) and the work of Robbie Case, currently at the Institute for Child Study in Toronto, can help. Vygotsky in his book entitled *Thought and Language*, published in the English translation in 1986, stresses the need to "study child thought along with the influence of instruction" (p.217). He distinguishes between the spontaneous concepts of the child, which lack the structure of a system, and the scientific concepts of the adult, which constitute a system of relationships. It's exciting for us in the 1990's to impose Edelman's jungle analogy on Vygotsky's adult cognitive "system"! Vygotsky uses the term "zone of proximal development" as "the place at which a child's empirically rich but disorganized spontaneous concepts 'meet' the systematicity and logic of adult reasoning" (p. xxxv). Case (1985) acknowledges the zone of proximal development but advocates that educational activities maximize a child's current structural level, while allowing him or her to move to higher levels.

The instructional approach taken by Case and Bereiter (1984) for mathematics and other academic subjects provides an interesting model. According to these investigators' approach, we should be asking the extent to which a specific symbol system *fits* with "the child's current level of intellectual development in a fashion that does not overtax his powers of working memory" (p. 154).

The need to reconcile Edelman's "jungle" with Vygotsky's "systematicity and logic of adult

reasoning" further reinforces the complexity of our task. Better this, however, than dealing only with simple surface issues. It is through the work of scientists such as Vygotsky, Case and Bereiter, that we gain the theoretical backing for what experienced instructors discover as they develop communication boards with children. I think of it this way. By offering many adult prepared structures and then observing as the child begins to use them, by making revisions in response to the child's ability to remember and by incorporating initiatives made by the child, a balanced and functional "jungle" will emerge. The child cannot create this "jungle" without the guidance of adults in the formative years. As children relate to gradually evolving organizations of their communication board, they learn what works for them. If they are given explicit instruction as to the options available and helped to evaluate the strategies that are most effective for them, they are well along the way to functioning in their unique and extremely powerful adult jungle. In the early seventies we had concern regarding the idiosyncratic attempts at communication of children whom no one could understand. This would still be a concern for a child in the nineties, but as children's communication skills develop and as they master the alternative strategies afforded by their communication system(s), idiosyncratic strategies become their personal way of realizing their potential.

I always have concern if one symbolic representational system is completely discarded when a new system is introduced. Why not help the individual use the best of every system? I have enjoyed watching Kari Harrington through the years as she collects strategies! Colour coding, semantic groupings, initial letters, grammatical classifiers,

alphabetical arrangements, personal associations, Minspeak strategies, Bliss strategies, letter encoding, word prediction: She uses them all! And continues to examine and enjoy considering new strategies.

Now, the organizational structure of communication boards belonging to persons who are totally eclectic in selecting strategies may not be evident to their facilitators! Producing such displays may take many hours of consultation with the AAC user. But we are not looking for simplicity or ready-made recipes when developing an individual's communication potential. We must remember that structure and help from adults is needed along the way. But we must remember as well, there should be a vibrant "jungle" at the end! Our goal is the individual's full potential for a "vast aggregate of interactive events"!

I would be delighted to hear from readers who are willing to give us glimpses of their "jungles" by telling us about their collection of strategies for organizing and retrieving words, phrases and sentences. And I extend a special invitation to anyone who has taken or given a course in strategy diversity for AAC users!

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